# A Participatory Game Design Approach for Children After Cancer Treatment

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## ABSTRACT

After stem-cell transplantation, pediatric patients must remain in aftercare due to a high risk of suffering from a plethora of life-threatening organic problems. In this phase, communication with the clinicians is key for an increased survival probability.

The multidisciplinary INTERACCT aims at developing a child friendly communication tool based on gamification principles in order to foster this important communication. Additionally, INTERACCT should stimulate exercises and treatment compliance. Finally, through analyzing gaming scores, INTERACCT should also act as a sensor for detecting problematic phases children are going through. Since the design of INTERACCT is key to its success, we present results from our user-centric and participative design approach using methods from design thinking and explorative design with school children aged 8 - 14. The results are game characters and story lines, which will inspire the game design of the INTERACCT computer games.

## Author Keywords

children; game design; serious games for health; user-centred design;

## ACM Classification Keywords

H.5.2 User interfaces: User-centered design

## INTRODUCTION

In this paper we present INTERACCT (Integrating Entertainment and Reaction Assessment into Child Cancer Therapy)[1], a multidisciplinary research project aiming at creating a communication tool for pediatric patients after cancer treatment with HSCT (hematopoietic stem cell transplantation) in after care. The communication platform should foster communication between patients and clinicians, but also increase motivation for treatment compliance by using appropriate designs and gamification elements. An important aspect of INTERACCT is the user centered research around entertaining and motivating schemes to reach this goal. According to the expertise of our medical partner, a certain level of distraction from their primary disease is appreciated by the young patients, therefore the use of games is obvious.

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[1]http://www.interacct.at/

The results of the presented research are situated on two levels. Firstly we present detailed results from participatory design sessions with children and split these results by age and gender. Secondly we provide insights on the application of participatory design methods with children in the context of game design, and we provide a reflection of when, how and with which target audience such methods can be applied. We further discuss if and how the presented results can inspire the design of INTERACCT, a serious games platform for health, targeted at children after cancer treatment.

## RELATED WORK

Health related computer games have been intensively researched in the near past, covering all kinds of desired positive aspects including education for coping with health problems, keeping up motivation when going through difficult times, strengthening treatment compliance, up to supporting therapy through physical exercises [19]. An important subgroup in this field are children and adolescents with any form of cancer, and since 2008 more and more game and multimedia projects for this particular group have been developed.

Re-Mission and its successor Re-Mission 2[2] are computer games specifically tailored to be played by children during and after cancer therapy. In a large randomized study the positive effect of plying Re-Mission on motivation and compliance of pediatric patients has been proven [14]. The game principle is based on fighting cancer cells inside an infected body, using abstracted weapons like chemotherapy, antibiotics and the bodys natural defenses. The game's purpose is to strengthen positive emotion, increase self-efficacy, and shift attitudes toward chemotherapy.

Combat [7] is a game similar to Re-Mission, where children can fight against the cancer cells in their bodies. Here empowerment is reached via identification with a fighting hero.

In [4] the authors present the game Patient Empowerment (PE) Interactive exercise video game, designed to stimulate the self-efficacy of pediatric patients with cancer. The game tries to transform physical excercises into mental empowerment through metaphors involving cancer, hospital personnel etc.

The authors of [13] present a game-like multimedia entertainment system primarily for educating children and adolescents of various age groups to learn about their illness and the necessary treatments. The paper describes the user centered design process for different age groups and focuses on age dependent requirements.

In [1] the authors describe a system for supporting children during cancer treatment to keep up with the curriculum of their school classes. The system focuses on mobile platforms like smart phones or tablets.

The Brazilian game called "Corrida da Saude" (Health Course) [8] aims at improving awareness about a healthy way of living in order to avoid developing cancer.

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[2]http://www.re-mission2.org/ (accessed May 21st 2014)

A different path is followed by the game "That Dragon Cancer" [11], which artistically reflects the fears and emotions of parents raising a young child with terminal cancer.

### Research through Design

The methodological approach of this research is informed by contemporary approaches in design research. We chose an approach where research is conducted through design. Such approaches have previously been framed as "design as research" (see [2] and [12]). They act as a means of knowledge construction and further result in reflective insights on the creative processes.

In arts Design Thinking is a well-established practice for conducting research through design. While the term Thinking refers to Aristoteles' episteme (intellectual knowledge) rather than making (poesis) and doing (praxis), Applied Design Thinking is the synthesis of thinking and doing, as Schön described in "The Reflective Practitioner" [21].

In computer science the term explorative design is used to describe an approach where design practices are utilized to facilitate research. The concept originated with John Deweys Theory of Inquiry [9], where he introduces the concept of "doing for the sake of knowing". Donald Schön built on the work of Dewey, when he observed that much of the knowledge needed and used in the design process is not known a priori, but acquired during the design process as a result of interacting with the object to be designed [21].

For game studies Stapleton defined the "RADDAR" method as an iterative loop where he reflexively defines research as design and design as research [20]. Regarding participatory game design approaches with children Moser found that creating low-fidelity prototypes in a workshop setting provides valuable insights for researchers while at the same time presenting a fun engagement for participating children [18]. It was also found that a user-centered approach can help to further reception and acceptance of a game-based solution for children with cancer [13].

### INTERACCT

INTERACCT aims at investigating the enrichment of traditional E-Health platforms with entertainment elements, aimed for motivating young patients and fostering medical communication between young patients and their respective clinicians. Although our approach may be generalized to any child related chronic disease, due to the special area of expertise of our hospital partner Childrens Cancer Research Institute (CCRI) at the St. Anna Childrens Hospital, INTERACCT focuses on patients being taken care of in the outpatient clinic after stem cell transplantation.

### Aims and Scope

We are currently developing an innovative, adaptive and entertaining/playful Web platform (INTERACCT) in a multidisciplinary approach at the interface of clinical research, design thinking and information and communication technology (ICT). Augmented clinician-patient communication

may enable the clinician to early identify behavioral changes which precede manifest symptoms of diseases. Furthermore the tool should be adaptive to developing problems, e.g. enhanced "drinking games" if fluid intake is decreasing. An entertaining user interface specially designed for juvenile patients should foster interaction with the tool and improve long term treatment adherence. In the long run, the use of INTERACCT could lead to earlier diagnosis, and thus to a better quality of care after HSCT.

The main project hypothesis is that the integration of specially designed playful elements into a Web based communication tool between clinicians and juvenile chronic patients fosters communication, compliance, and therapy. We hypothesize that the frame of a game can help sustain motivation in using such a tool.

INTERACCT therefore should have the look and feel of modern entertainment platforms, including various elements of entertainment, challenges, games and social aspects, etc. Seen from the children's perspective, delivers mainly entertainment, and is a source of challenges, competitions, empowerment and fun. The E-Health aspects of fostering compliance, communication, and treatment should be visible, but not dominating.

### Example Use Case (fictional)
This chapter should depict the process of how the patient-doctor interaction is supported by INTERACCT, and how the system can improve the treatment. This example was created in close collaboration with a medical expert for stem cell transplantation after care.

*Patient X is 16 years old and was diagnosed leukaemia 2 years ago. After chemotherapy and receiving an allogeneic stem cell transplantation, his leukaemia was controlled. Patient X was released from the hospital into home care and got access to the INTERACCT web platform. For his after-care treatment, Dr. Y assigned him the standard profile, in which he had to report on a daily basis: overall condition, fluid intake in ml, possible problems or pain during fluid intake, stool frequency, possible problems or pain regarding stool and how his appetite was. Additionally, he was assigned a mini-game which encouraged him to do some simple physiotherapy exercises for about 30 minutes every day.*

*After 4 weeks of data submission, Patient X obviously started feeling bad, as his overall condition value dropped compared to the first weeks, and because he only finished half of his physiotherapy mini-game-sessions. The medical experts started looking at data in detail, and found out that the fluid intake decreased from 2000ml/day to 800ml/day. The physician asekd Patient X to come to the clinic, to examine his condition personally. During this examination Patient X pointed out that he didn't enjoy drinking water because it hurts in his throat. The physician therefore commences further investigations and discovered a fungal throat infection (which is a common side effect of chemotherapy). Therefore the physician assigned a mini-game which should encourage Patient X to take a sip of water every time a certain event*

*is happening in the game. This event is connected with a positive in-game-reward, therefore the patient started reinventing the idea of taking a sip of water with something positive, as well as having increased fluid intake.*

This - fictional - example draws an outline how the system could improve the patient condition constantly. If the state of reduced fluid intake would remain hidden for several weeks, serious kidney problems could be a consequence. The physician has access to actual, rich health data (direct patient input & laboratory results in one visualization) which eases the process of deciding on eventual therapy steps.

### EXPERIMENTAL RESULTS
The goal of INTERACCT is to develop a game world which appeals to a young target audience. Due to the nature of the primary disease, the target audience is highly heterogeneous. It includes children aged 8-18 with differing ethnic background and from different social classes. Children in the target audience are further separated by changes in health, well-being, psycho-motoric and psycho-social developmental status due to the HSCT treatment. The INTERACCT game shall be designed to provide high adaptability to accommodate changing circumstances in health, age and social context of patients.

We have so far conducted a review of relevant projects target at children and young adolescents, employed explorative design approaches within the project team, and conducted a quantitative survey (full results forthcoming in late 2014). In the survey we compared groups of young gamers, school children and children after cancer treatment regarding their gaming habits and individual preferences. The results of the survey so far point towards environments which allow exploration and adventure. We further confirmed that there is a wide range of preferences regarding visual styles and that children prefer imaginative characters over realistic representations. We have thus settled on a fantasy island (see Figure 1) as the environment for the game. The specific goal of the used participatory design approach is to find characters, stories and game mechanics within this given environment, which are interesting to young players.

### PARTICIPATORY DESIGN EXPERIMENTS
Following we present the results from qualitative design experiments conducted in two public schools in Vienna, Austria. The overall sample is comprised of 81 children aged 8 to 14. The qualitative evaluation was carried out in two schools, an elementary school and a secondary school. For the analysis of results in the following the sample is split into 4 groups; 17 female participants aged 8-10, 17 male participants aged 8-10, 29 female participants aged 12-14 and 18 male participants aged 12-14.

We visited classes in the two schools during drawing lectures which span two hours. There we briefly introduced the theme; children should draw comic strips of characters and their adventures on an island (see the preconditions defined beforehand). They were only given the context that these characters

**Figure 1. A bright and happy version of the island players shall be able to explore in the INTERACCT game**

will be used in a video game and some hints about possible drawing techniques were given. They were handed two pictures of the island (see Figures 1 for the bright version of the island, a second version of the island depicts a dark and gloomy version of the same island) as inspiration and a blank comic strip with six panels for drawing their characters. They were encouraged to be imaginative and were told that everything is allowed to be drawn and that all ideas are welcome. The process of drawing was then supervised by members of our project team together with the classes' teachers.

For the evaluation we clustered the drawings and we present a summary of the findings and representative example pictures for the four groups separated by age and gender.

### Female, Age 8-10

The girls developed three different character types, including (i) pure fantasy characters, (ii) fruit and plant characters, and (iii) special animals. Also, humans often appear in the stories. Drawings from the girls are usually colorful, with dominating colors being pink, yellow, red, blue and green (see Figure 2).



**Figure 2. Characters, female 8-10.**

Colors are also often pastel, and girls seem to lay more emphasis on the background compared to boys, including floor, sun, clouds or trees, even if they are irrelevant for the story.

Characters are mostly friendly looking, having round and soft features. Most of them exhibit friendly human properties, often positive traits. Characters are active and like to do things, have heart-like shapes, hair is important, often growing. Animals include dogs, snails, turtles, ants, cats, butterflies and squids. Plant animals include mostly edible plants like bananas or cucumbers, but also clover leaves. Girls prefer complex story lines including fitting start and end. An important theme is finding friends, converting bad characters to do good, and saving the innocent. Stories are mainly driven by changing characters instead of weapons or tools. Antagonists are often classical fantasy beings like monsters, aliens or dragons, the issued threats mostly involve being eaten up.

### Male, Age 8-10

Boys in this age group primarily focused on established fantasy characters like monsters, dragons, aliens and robots. Dragons appear frequently, since they can be used as positive, but also as dangerous characters. Some also described fantasy animals and plants, which had magical spells and other special abilities. The most used animals were birds, dogs, sharks, monkeys and snakes (see Figure 3).



**Figure 3. Fantasy and animal characters, male 8-10.**

Fantasy food as invented by the boys is dominated by sweets, ice cream or fast food. In comparison to the girls in the same age group real people had less presence in the stories. Recurring traits of the characters include multiple arms or heads, squared and triangular shapes, many teeth or spikes, and a generally evil or dangerous appearance. Boys tended to use less colors and preferred to use darker colors including shades of blue, black, green, brown and red. The characters often were equipped with tools and weapons, and they had special abilities like jumping very high, climbing, flying or shooting with weapons or spikes. Boys in this age group were less concerned with an overall story but rather focused on the appearance and abilities of many different characters each. The main goal of the boys is to defeat enemies, fighting is the main storyline. Fights should be enhanced by special weapons, abilities and tools. However, there are exceptions to the above described observations, boys using pastel colors, using a detailed, positive story line with detailed backgrounds, and friendship as main motive, as well as girls drawing monsters or aliens without an embedding story.

### Female, Age 12-14

Girls in this group primarily developed three different types of player characters: (i) fantasy beings, (ii) fruit characters and (iii) animal characters with special traits. Paintings in this group were very colorful with high use of the colors yellow, pink, red, blue and green. The developed characters are mostly cute but often also have a dark and dangerous side. This means that they should have the ability to change both visual appearance as well as abilities and character traits. Summarised many participants want an ambivalent character who can be good and bad depending on the situation. For example a cute rabbit was painted who could poison people with his carrots. The most used animal in this group are penguins followed by lions, giraffes, bears and rabbits. The fantasy being were mostly round and moved by rolling, flying or jumping (see Figure 4).
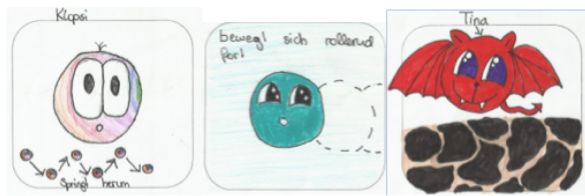


**Figure 4. Round characters, female 12-14**

For girls in this group, beating enemies was generally more important than interacting with fictitious friends. If they painted friend characters they were cute and benevolent. Enemy characters usually correspond to the story and player character. For example a cute lion battles a cute duck or a lemon fights a banana. Some participants also focused on collecting items including coins, food, hearts and stars. These collectible items can then be spent on abilities, weapons and cloth for the player character. The prevalent game idea in this group was to beat an enemy in order to free a friendly character.

### Male, Age 12-14
The drawings of boys in this age group can be broadly structured into three groups, (i) fantasy beings, (ii) fictitious plants and (iii) fantasy animals. Most of the participants did not use colors but submitted black and white drawings. Similar to the characters designed by girls in this age groups, the characters drawn by boys can visually change between a good and an evil version. They grow with the player and can fully change their identity when need arises. The designed characters are rather militant and cool than cute and friendly like the girls' characters. The most common game goal of participants in this group is beating an enemy. Fighting usually is the core of the drawn story. Most game ideas also involve awarding points, which can be used to buy lives, energy and weapons. Two juxtaposed game concepts mentioned by this group are on the one hand saving the nature and plants on the island and on the other hand killing and wiping out all plant life (see Figure 5).

### CONCLUSIONS
In this paper we present the first results from the research INTERACCT, in which we develop a gamified communication tool for children and adolescents after HSCT. The biggest



**Figure 5. Plant environments, male 12-14**

challenges are the fact that the INTERACCT should work for different age groups, genders, and cultural backgrounds.

The presented experimental results from design workshops with children of different ages and sex show the influence of both variables. While for boys, mainly fighting and weapons are of importance, here using often monocolors or black and white, girls lay more focus on coherent story lines and relationships with more colorful drawings. A common ground is the use of animal and plant characters and the use of exaggeration and supernatural abilities.
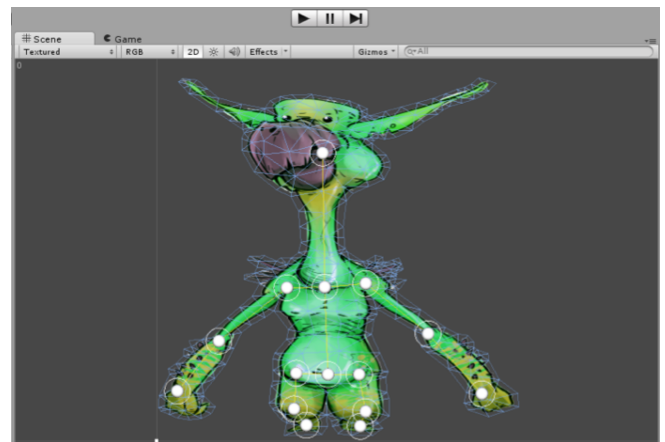


**Figure 6. Defining animations for an in-game character.**

The main different property between age groups is that older children design more complex characters and story lines, characters become more adaptive and versatile, gain depth and ambivalence. However, character types remain basically the same.

The participative approach proved insightful and will help shape the core gameplay and visual style of INTERACCT. A first set of charcters is integrated in the game at the moment of writing (see Figure 6). When finished, the game will be tested with patients at St. Anna Children's Hospital in Vienna.

The use of user-centred and participatory design methods is helpful in early stages of a project, where it helps to find a general direction for the design. As in the presented research a later stage of the project can even benefit more from such an approach because more focused tasks can be given to children alongside first materials for inspiration.

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